

**Integrated Healthcare System for Children with
Children's Rehabilitative Services (CRS) Eligible
Conditions**

**PART 1: Summary of Input from Family Members and
Advocates**

PART 2: Summary of Input from Providers

**A Report Prepared by
St. Luke's Health Initiatives (SLHI) for
Arizona Health Care Cost Containment System (AHCCCS)**

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Integrated Healthcare System for Children with Children's Rehabilitative Services (CRS) Eligible Conditions

PART 1: Summary of Input from Family Members and Advocates

Background Information

From the AHCCCS website:

Arizona's Children's Rehabilitative Services (CRS) was started in 1929 to serve children with complex health care needs who need specialized services. A list of specific conditions determines whether a child is eligible for CRS. Although CRS is a part of the Arizona Medicaid program, CRS services have not been managed within the AHCCCS health plans. As a result, a child with complex needs was enrolled in a minimum of two separate systems of care—one for well-child and primary care, and the other for specialty care through CRS.¹ Children with other conditions, including developmental disabilities or behavioral health needs, are sometimes enrolled in several systems of care.

This can be confusing for families and providers. Coordinating care for CRS children became a challenge for AHCCCS, and clearly the burden placed on families has also been significant. Effective in January 2011, a process was begun to integrate CRS into AHCCCS. This offers a way to ensure access to specialty care and the opportunity to consider a more efficient coordination of health care services. AHCCCS is working to create a specialty health plan that would manage care not only for CRS conditions but also for other medical and potentially behavioral health conditions as well.

Raising Special Kids (RSK) and St. Luke's Health Initiatives (SLHI) have been assisting AHCCCS in obtaining input on the proposed healthcare integration from families who have children with special health care needs. In September 2011, phone interviews were conducted with 18 families whose children receive services from CRS in Flagstaff, Phoenix, Tucson, and Yuma; five of these were conducted in Spanish. The families were identified by the CRS Clinics. In addition, a focus group and one interview were conducted with advocates; five people participated. Results of the family member and advocate input are included in this report.

Focus groups and interviews have also been conducted with providers of primary care and specialty care services, including one that focused specifically on behavioral health. The results of this input process are reported in Part 2.

Overall Findings and Observations

There were some pervasive themes that threaded through the focus group and interviews. Family members and advocates want a system in which:

¹ Note: Some families have chosen the same AHCCCS health plan for their well-child/primary care as their child is enrolled in for CRS specialty services. In this case, the child would be enrolled in only one health plan but would still have two separate health plan membership cards.

- There is access to a full range of quality primary care and CRS specialty services, ideally as close to home as possible and with as short a wait as feasible.
- There is improved coordination of primary care and CRS specialty services. While integration is appealing, families do not want to give up their current primary care provider, who understands and serves their family well, may be seeing other family members, and is conveniently located.
- Other healthcare services are integrated if it makes sense to do this, most importantly behavioral health, as long as this does not result in a loss of services or service quality.
- Families have a choice of providers first and foremost, but also a choice of health plans, if feasible.
- Co-location of primary care and CRS specialty services is an option, but not a requirement. Most important is having access to primary care in the home community and being able to take other children in the family to the same place.
- CRS specialty services are co-located at least for children who need services long term and whose needs are more complex. It may be that not all children need co-located services.
- There is access to care coordination, with the option of being able to do this one's self. Care coordination is most needed initially, when the child is young and/or newly diagnosed, when surgeries and other specialized procedures are scheduled, and at transitions.
- There is an option for the young adult to stay in the integrated health plan past age 21, if circumstances indicate that this is needed and in the best interest of the young adult. A transition plan should be developed and implemented.
- Families have the option of taking all their children to the same primary care provider, mainly in the provider's private office, but possibly in the CRS clinic if this does not slow down the care of children with special health care needs.

Findings and Observations: Family Interviews

This section summarizes the comments shared in phone interviews with families using CRS services, and includes written comments from one other parent. Comments were grouped by topic and are not necessarily listed under the question that was in discussion when the comment was made.

Characteristics of Children of Families Interviewed

Of the families interviewed, 14 families had one child enrolled in CRS, three families had two children enrolled in CRS, and one family's child was deceased. The ages of the children ranged from 11 months to 19 years. Families lived in Avondale, Clarkdale, Flagstaff, Kingman, Peoria, Phoenix, San Luis, Tucson, Winslow, and Yuma. Most (6) of the 15 who responded to the question reported that they traveled 11-20 miles to the CRS Clinic; the range was under five miles to 150 miles. Eleven self-identified as White and six as Hispanic. The primary language of 13 was English; the primary language of the other five was Spanish. There were a number of different diagnoses and children participated in a wide range of CRS Specialty Clinics. Six each primarily attended the Phoenix and Tucson CRS Clinics; four attended the Flagstaff Clinic; and two attended the Yuma Clinic. Seven had been receiving CRS services more than ten years; five had been receiving services 6-10 years; two had been receiving services 3-5 years; one had been receiving services 1-2 years; and one had been receiving services less than one year. Twelve of the 18 families had a child who was also in the ALTCS Developmental Disabilities Program (DDD); six had a child enrolled in the ALTCS Elderly and Physically Disabled Program (EPD); four had a child covered by Medicare; and three had a child enrolled in the behavioral health system via a Regional Behavioral Health Authority (RBHA). Many did not know if their child was covered by Medicare or not.

Integrating Primary Care, CRS Specialty Services, and Other Healthcare Services in the Same Health Plan

Of the 18 families interviewed, 15 responded that integration was a good idea; one did not support integration; and two were unsure. Benefits included the following:

- One place to call
- Clearer who is covering which services
- Might facilitate billing
- Less paperwork

One respondent commented that in the past, “My son only had one health plan due to his developmental disability and eligibility for Title XIX. This was much easier to understand not only for me but for my primary care provider as well. When I go to specialist appointments now, I am not sure what card to give, is this CRS related or not?...If there is one health plan to deal with, service may be scheduled faster rather than trying to figure out who gets what.”

Some of the families had private insurance (and, in one instance, TriCare coverage). They were not sure how this would work for them. One respondent commented that her child sees CRS specialists in their offices rather than at CRS using her private insurance; she wants to continue to do this.

Some were concerned about making the transition to an integrated health plan, even though the concept was appealing. One respondent noted: “What we have in our family works.”

Some children in families who were interviewed are also enrolled in programs such as ALTCS EDP, ALTCS DDD, behavioral health, and/or Medicare. When asked if it would be helpful for these programs to be in the same health plan as primary care and CRS specialty services, nine of the 13 to whom this question was applicable said “yes,” and four said “no.” It was most difficult for respondents to visualize how this would work for DDD, notably habilitation services. One said that DDD needs to be kept separate because they know the family and are working with both a child in the family and an adult sibling. Another commented that their DDD support staff person helps with the paperwork that the family has to submit to CRS. On the other hand, one respondent, whose child receives services from DDD, said, “I will say whatever can be done to make my life less stressful let’s do it. Families have an additional stress level along with having to deal with various agencies, arranging for added healthcare appointments and other appointments to get the needed services for their child. I see that all services should be integrated into a single health plan. The less additional agencies there are involved the better and less stressful to the family.”

Choice

Families were asked how they would feel about not having a choice of health plans, as long as they had a choice of providers. Most (12 of 18) thought that would be acceptable; three did not; and three were unsure. Respondents stressed the importance of having a wide range of choices of providers, as this is a factor in selecting a health plan now. They also stressed the importance of the coverage provided, as this, too, is a factor in selecting a health plan now. One respondent commented on the necessity of flexibility in the health plan; her child needs specialty care that is only available out of state and would need to make sure that the health plan provides this coverage. Another noted that, regardless of

whether there would be one choice of plan or more, more providers are needed, especially in Northern Arizona.

Co-Location

Slightly more than half (10 of 18) favored co-location of primary care and CRS specialty services. The Tucson CRS clinic already has co-located services, albeit not necessarily via the same health plan. Some noted that they liked their child's current pediatrician and did not want to switch, even if services could be co-located. Selecting the pediatrician was really important to many of the respondents. One noted that their family planned visits to their pediatrician on Saturdays and that the CRS clinics were not open on Saturday. One commented that their pediatrician's office was close to the CRS clinic and that was good enough. Families from areas of Arizona that were not in close proximity to a CRS clinic raised the issue of access to primary care. One respondent noted, "Because of the geographical location of the CRS clinics, it would be difficult for some to have their primary care there. Community based services for primary care is very important to families...Also parents need to work and having primary care locally is critical in allowing those parents to work and care for their child."

When asked about co-location of other healthcare services with primary care and CRS specialty services, most (15 of 18) stated that they preferred to receive at least some services in separate locations. The main factor was being able to see specialists in their private offices, as it is sometimes quicker to get an appointment and more convenient. One respondent noted that she would like for her child to continue to receive therapies in the home, as now occurs through DDD.

With respect to which services should be prioritized for co-location, the following were mentioned by at least one respondent: intake, cardiology, neurology, orthopedics, pediatrics, pulmonology, therapies, and wheelchair clinic. When families have to travel long distances for services, it is convenient to have them co-located.

At least one respondent brought up the issue of expertise, stating that finding the right specialists was more important than where services were provided—in the CRS clinic or in the community.

At least one respondent brought up the issue of the pediatrician being on the team, regardless of whether services were co-located or not. She thought it would be beneficial to have this continuity of care. Having access to the same medical records was also seen as a benefit, but it was noted that this could be done whether or not services were co-located.

Access to CRS Specialty Services

Most (15 of 18) respondents stated that they have sufficient access to CRS specialty services. Two respondents noted that their children have rare conditions and the only specialists are outside of Arizona; they have CRS referrals for services from these specialists. A few expressed concerns about the quality of particular aspects of the care under the current system.

Families were asked what was most important—getting services close to home, getting services and appointments quickly, or getting services from the best specialists for the child even if not close to home. Most ranked getting the best services as number one, followed by getting services and appointments quickly, and getting services close to home. Suggestions for improving access included use of mobile services for outlying areas. One respondent commented that the answer depends on the

situation—that is, whether it is an emergency or not.

Quality

Most (15 of 17) were very satisfied with the qualifications of their CRS providers, with a few exceptions that were noted. One respondent noted that sometimes the appointments feel rushed.

Most (15 of 17) were also very satisfied with the quality of CRS services, with a few exceptions. The only service mentioned by more than one respondent was the wheelchair clinic, with concerns being expressed about delays, costs, knowledge of products, and the process in general.

CRS: What Should Be Preserved/Improved

One respondent noted that the “multidisciplinary clinic is what we grew up with...you have phone numbers, access to nurses, and you can always call and talk to someone...people at CRS deal with people with orthopedics every day so my questions are not bizarre.” Another said, “Everyone is very child-oriented and tries really hard. I like the way doctors communicate. My son has 17 doctors and they share information about him on computers.”

Several of the respondents expressed concern that CRS specialty services would be lost in a move toward integrated healthcare. They value what they have. In particular, they value: committed and caring staff, the intake process, availability of someone to talk to about their situation, referrals, personalization of services, continuity, selection of providers, how providers work together, everything in one place, long term relationships, and camaraderie with other families.

When asked what would make it better, one or more families mentioned the following: recognition of changes in the child over time especially as they approach young adulthood, increased knowledge of community resources, increased opportunities for parent-to-parent interaction, fewer cancellations (surgery clinic), quicker access to appointments, all specialists in one location, less turnover (specifically among physical therapists), improved access to care (specifically physical therapy in rural areas), more frequent clinics, and more services (notably in Northern Arizona).

Coordination

Most (14 of 18) thought that support for planning and coordinating appointments, services, and care was very important. It was noted that care coordination is most important during the early years, when there are multiple children in the family, when surgery is being scheduled, and when the family is coming from a distance for multiple appointments. Some noted that family members may be able to provide their own care coordination in certain situations, but care coordination should be offered to all. Some noted that a care coordinator should have some medical background, or at least knowledge of the field.

Extension beyond Age 21

Most (16 of 17) supported extension of CRS services beyond age 21. Some commented that it should depend on the person’s situation. Others said it depends on the cost. One respondent commented on the fact that her child would be unable to obtain insurance as an adult and that his healthcare was dependent on being able to stay in CRS. Finding a knowledgeable specialist in the adult healthcare

system may also be difficult for many conditions. This can lead to life-threatening situations for vulnerable young adults. Continuity of care was also mentioned; if the same physicians were available that would help, whether or not they were affiliated with CRS. Regardless, better transition to the adult healthcare system is needed.

Inclusion of Other Family Members

Opinions on inclusion of siblings and other AHCCCS-eligible family members in the same integrated health plan were mixed. Ten of 18 favored the concept, but some had some questions and reservations; five were opposed; and three were unsure. The major benefit noted was convenience for families. Concerns mentioned were: reduction of current benefits for non-CRS eligible children in the family, that it would require adding many more physicians to CRS, increasing wait time, and diluting the focus on children with special health care needs. It did not appear as if inclusion of siblings and other family members in the integrated health plan was something particularly important for families interviewed, if they could continue to use the same provider for all their children.

Other Comments

One respondent noted that the CRS program has gotten more confusing for families over time and was unaware if there was a handbook for families. She said that it has also become confusing for providers. Clarification is needed on who pays for what.

Most of the other comments focused on advocacy for continuing access to CRS specialty services. Families depend on these services and are fearful that they might be reduced or eliminated. One respondent commented, "CRS has been a life saver to my family. When I bring my son to the CRS clinic, I feel confident that he is receiving quality care. To me, that means a lot. They are people that work with children every day and have the skills to do so. It will be difficult in a few years when my son ages out of CRS, who will he see, who can I trust? CRS is something very special in Arizona and we need to keep the integrity of the program and if it can extend out for adults with special healthcare needs, that would be amazing."

Findings and Recommendations: Advocate Interviews and Focus Group

This section summarizes the comments shared in phone interviews and a focus group with advocates who are family members of children with special health care needs or are working with families of children with special health care needs. The process was not designed to lead to consensus nor was there any form of voting. This report is not a transcript of the focus group and interview responses; comments were grouped by topic and are not necessarily listed under the question that was in discussion when the comment was made.

Integrating Primary Care, CRS Specialty Services, and Other Healthcare Services in the Same Health Plan

Participants/respondents thought that having primary care and CRS specialty services integrated in one health plan would be beneficial to families of children with special health care needs, particularly because it might reduce disputes about whether a service is necessary and who pays for it. It was noted that integrating these services and having a single medical record would promote coordination among

providers and continuity of care. It might have the added benefit of reducing paperwork and bureaucracy.

Participants thought that integrating behavioral health into the same health plan might be beneficial, also. It might improve coordination of care, particularly medication management. There were no comments specifically related to integration of EDP or Medicare. There were mixed opinions about integrating DDD.

Choice

There were mixed opinions about the importance of having a choice of more than one integrated health plan. If there were a choice, families might be able to stay with the plan they are currently in and where their other family members go (assuming that health plan was a successful bidder). On the other hand, having multiple integrated health plans would require educating many different people and systems about the needs of children with special health care needs. Regardless of whether there is one or more than one, participants stressed the importance of having a choice of doctors and having access to all the needed specialties for families throughout Arizona.

Co-Location

A question was raised about choice as it relates to co-location: Could families have a choice of using the primary care provider at the CRS clinic or using someone in their community? If the only pediatricians available to them were the ones at the CRS clinic, this would present a problem for families, particularly those who do not live close to the CRS clinic. They need a primary care provider who is in their community and close to their home. Additionally, it was noted that as many specialists as possible should also be in the family's community and close to their home. As in the family interviews, concern was expressed about having to switch pediatricians, once the family has found someone who really understands their child, the child's condition, and the family's situation. It was noted that families often want to be able to take all their children to the same primary care provider.

With respect to co-location of specialty services, participants thought that co-location of some services was more important than others. For children who need access to multiple specialists, co-location of these specialists would be beneficial. Examples of services that might be beneficial to have co-located included nutrition and social work. Lab services might need to be available close to home for children who require frequent blood draws. The main point was that the configuration of services should be based on the needs of children and the convenience of their families—what they use, how often they use clusters of services, and where they are coming from.

Range and Quality of Services

Children with special health care needs and their families need access to a broad range of quality services, such as those currently provided by CRS. More behavioral health services are needed for children with special health care needs, their siblings, and other family members. Some highly qualified specialists in Arizona are not CRS providers and need to be, e.g., pediatric audiologists. The integrated health plan needs to have a focus on the family, not only the child who has a CRS eligible condition.

Coordination

Care coordination is most needed initially, when there is going to be a surgery or other specialized procedure (e.g., cochlear implant), and when transitioning (e.g., home after an inpatient stay, into the adult healthcare system). The care coordinator needs to be familiar with the various systems that impact the family and resources available to the family in their local community. The care coordinator needs to understand the family, its strengths, and potential natural supports. What the care coordinator knows is more important than their degree.

It was noted that some would say the primary care provider should be the care coordinator, but some participants did not think most families would agree. Often a specialist or someone who works closely with a specialist might be a better choice for a child with complex needs. It was noted that some families are able and prefer to serve as care coordinator themselves. This should be possible for them. Care coordination should be offered but not required.

Concern was expressed about care coordination slowing down the process; it should not add another level of approval to the process, but rather should facilitate access to needed services and supports.

Extension beyond Age 21

Transition to the adult healthcare system is challenging for many young adults with special healthcare needs and their families. Participants supported extending CRS services past age 21, but noted that not all would need this and that it should be done in the context of developing a transition plan. It would be necessary to determine what would be covered and what would not.

When asked whether young adults should be able to continue to come to the CRS clinic or just be covered by the same health plan, several commented that staying in the same health plan was more important. This might encourage health plans to include adult healthcare providers and foster their familiarity with CRS eligible conditions. Coming to the CRS clinic might not be the best option for young adults, as the clinics are focused mainly on children, although maybe they could come on a different day.

Inclusion of Other Family Members

There were mixed comments related to inclusion of other family members in the integrated health plan. Participants noted the advantage of being able to use the same primary care provider (as many families do now), but did not want to overburden the CRS clinics if primary care and CRS specialty services were to be co-located. There was agreement that families should have a choice.

Other Comments

The Arizona Early Hearing Detection and Intervention (AzEHDI) Program provided written comments (document dated 5/19/11). They asked that their comments be considered by AHCCCS in future planning.

It was noted that some children need a coordinated approach (including integrated health plan, co-location of services, and care coordination) more than others do. Ideally, they could receive coordinated health care in their own communities, or at least nearby. One option might be to develop expertise in

local communities, so that local providers could provide needed services to as many children as possible. At a minimum, the child's local doctors should be part of the multidisciplinary team, with appropriate reimbursement. Other options that should be explored include mobile clinics and telemedicine. Further conversation about this is needed.

It was noted that children's situations change over time. Their needs and those of their families are fluid and the system needs to be created to take this into account.

Attachment 1
Family Survey

Background Information

1. Name of person being interviewed and relationship to the child:
2. Name of child (or children, if applicable):
3. Date of birth/current age of child:
4. Closest city/town to their home:
5. Race/ethnicity of child (voluntary):
6. Primary language of the family:
7. Diagnosis (es):
8. Which CRS Specialty Clinic does your child go to?
☐ Flagstaff
☐ Phoenix
☐ Tucson
☐ Yuma
9. Which of the CRS Specialty Clinics does your child use? List all that are mentioned.
10. How far do you have to travel to reach the CRS Clinic Site?
☐ Under 5 miles
☐ 6-10 miles
☐ 11-20 miles
☐ 21-30 miles
☐ 31-40 miles
☐ 41-50 miles
☐ More than 50 miles. Specify approximate distance:

11. How long has your child been receiving services from CRS?

- ☐ Less than 1 year
- ☐ 1-2 years
- ☐ 3-5 years
- ☐ 6-10 years
- ☐ More than 10 years. Specify approximate length of time:

12. Do you have private health insurance that covers any of the following people? Check all that apply.

- ☐ The child who is enrolled in CRS
- ☐ Other children in the household
- ☐ You and/or your spouse
- ☐ None

13. Are any of the following people in your household enrolled in AHCCCS for their general medical (acute) care? Check all that apply.

- ☐ The child who enrolled in CRS
- ☐ Other children in the household
- ☐ You and/or your spouse
- ☐ None

14. When your child who is enrolled in CRS is ill (e.g., has an earache or sore throat), what health plan are you using?

- ☐ Care 1st Arizona
- ☐ Maricopa Health Plan
- ☐ Health Choice AZ
- ☐ Mercy Care Plan
- ☐ DES/CMDP
- ☐ Phoenix Health Plan
- ☐ Pima Health System
- ☐ University Family Care
- ☐ Bridgeway Health Solutions
- ☐ Arizona Physicians IPA
- ☐ Other. Specify where they get care:
- ☐ Not sure

15. Do you happen to know if your child is covered by Medicare?

- ☐ Yes, the child is covered by Medicare
- ☐ No, the child is not covered by Medicare
- ☐ Not sure

16. Is your child enrolled in any of the following programs? Check all that apply.

- ☐ ALTCS Elderly and Physically Disabled Program (EPD)
- ☐ ALTCS Developmental Disabilities Program (DDD)
- ☐ Behavioral health/RBHA (such as Magellan, CPSA, ...)

Interview Questions

17. If your child receives well-child care from one health plan and CRS specialty care from a different one, would it be better to have all health care services available under one plan? (You would have one place to call for questions and authorizations for your child's care).

☐ Yes ☐ No ☐ Not sure

Why or why not?

18. For your child who is enrolled in more than one program (see answers to Q15 & Q16), would it be helpful to your family if ALL the services were provided through the same health plan?

☐ Yes ☐ No ☐ Not sure ☐ Not applicable

What are your thoughts about that? (e.g., most important programs to integrate, concerns about integration)

19. If all your child's health care services were covered under one plan, there might not be a choice of health plans, but you would still have a choice of doctors. Would that work for your family?

☐ Yes ☐ No ☐ Not sure

Why or why not?

20.a. Would it be helpful to have your child's primary care physician (e.g., pediatrician) at the CRS clinic?

☐ Yes ☐ No ☐ Not sure

b. If all your child's healthcare services were provided by one plan, would you like the choice of having all services in one physical location?

☐ Prefer one location for all services

☐ Would prefer the option of getting some services in a different location, for example, seeing one of your child's CRS specialists in their private office or seeing specialists who are not part of the CRS clinic in a different community location?

c. At a minimum, which services would you like to see provided in one location?

21. Do you have enough access to the CRS specialty care that your child needs?

☐ Yes ☐ No ☐ Not sure

If not, what would make it better?

22. Sometimes families have a hard time getting to the CRS specialists because they are not located close to home. That means making tough choices. Please rank these from one to three, with one being your top choice. What is most important to you?

Getting services close to home

Getting services and appointments quickly

Getting services from the best specialist for my child, even if not close to home

Comments:

23. How satisfied have you been with the qualifications of CRS providers?

- ☐ Very satisfied
☐ Somewhat satisfied
☐ Not very satisfied

What would make it better?

24. How satisfied are you with the quality of CRS services your child receives?

- ☐ Very satisfied
☐ Somewhat satisfied
☐ Not very satisfied

What would make it better?

25. What is working in CRS that should be preserved?

26. What would make CRS better?

27. How important is it that you have some support for planning and coordinating your child's appointments, services, and care (care coordination)?

- ☐ Very important
☐ Somewhat important
☐ Not very important

When would care coordination be most helpful to you and your child?

28. Right now, CRS eligibility ends at age 21. At 21, should the person:

- a. Be able to stay in the CRS program? ☐ Yes ☐ No ☐ Not sure
b. Have the option to remain in the same health plan? ☐ Yes ☐ No ☐ Not sure

Comments:

29. If primary care and CRS specialty services are included in the same health plan, do you think other children in the family and parents who are also on AHCCCS should be able to enroll in the same plan?

☐ Yes ☐ No ☐ Not sure

How would that be helpful for your family?

30. Is there anything else that you would like to say to the team that will be working on plans related to an integrated health care delivery system for your child?

Attachment 2

Focus Group Questions

SLHI is working with AHCCCS to obtain family/consumer input into the integration of CRS specialty services and primary care medical services for children currently eligible for the CRS Program. In collaboration with Raising Special Kids, we have conducted interviews with families of children receiving services from the CRS Clinics in Flagstaff, Phoenix, Tucson, and Yuma. We will add your input to the information we have obtained from them and share it with AHCCCS. There will also be a series of provider input meetings and an on-line survey will be posted to the AHCCCS website in the near future.

1. AHCCCS is considering integrating primary care and CRS specialty services for children currently eligible for the CRS Program under one health plan (not necessarily in one location and only not necessarily only one health plan option – we'll talk about these issues later in the meeting). What questions does this raise for you? What do you see as the benefits of integration? What do you see as possible disadvantages or what concerns do you have?
2. In addition to primary care and CRS specialty services, some eligible children also receive Title XIX-funded behavioral health services, EDP services, and/or services related to developmental disabilities. Others receive Medicare services. Which of these should also be integrated into a single health plan? Which should not? How would integration of these programs/services be beneficial to families? Or not?
3. At this time, only one AHCCCS health plan is contracted to provide CRS specialty services but families have a choice of AHCCCS health plans for their children's primary care services. If these services were integrated, do you think there should be more than one choice of integrated health plans? Why or why not?
4. Let's talk about the location of services. Do you think that primary care services should be co-located with CRS specialty services? Why or why not? At a minimum, which services should be located in the same place? Which are more appropriately provided in other locations, such as the physician's private office?
5. How satisfied are you with the range and quality of CRS specialty services? What would make it better? What is working that should be preserved?
6. Families have been telling us that care coordination is important, particularly in some situations and at certain times, e.g., prior to a surgery. In an integrated health plan, what do you think care coordination should include? Who should be the care coordinator? What qualifications should they have? Should everyone receive care coordination? When/how long should it be provided? What are your concerns about care coordination?
7. Right now, CRS eligibility ends at age 21. Do you think it should be extended? For all, or only in certain circumstances? If extended, would this be at the CRS clinic or other locations

within the same health plan?

8. If primary care and CRS specialty services are included in the same health plan, do you think other children in the family and parents who are also on AHCCCS should be able to enroll in the same plan? Why or why not? Should they be seen in the CRS clinic or elsewhere?
9. Is there anything else that you would like to say to the team that will be working on plans related to an integrated health care delivery system for children who are eligible for the CRS Program?

Integrated Healthcare System for Children with Children's Rehabilitative Services (CRS) Eligible Conditions

PART 2: Summary of Input from Providers

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This can be confusing for families and providers. Coordinating care for CRS children became a challenge for AHCCCS, and clearly the burden placed on families has also been significant. Effective in January 2011, a process was begun to integrate CRS into AHCCCS. This offers a way to ensure access to specialty care and the opportunity to consider a more efficient coordination of healthcare services. AHCCCS is working to create a specialty health plan that would manage care not only for CRS conditions but also for other medical and potentially behavioral health conditions as well.

Raising Special Kids (RSK) and St. Luke's Health Initiatives (SLHI) have been assisting AHCCCS in obtaining input on the proposed healthcare integration from families who have children with special healthcare needs and advocates. Results are included in Part 1 of this report.

In addition, SLHI conducted a series of provider focus groups to obtain input from those who provide primary and/or specialty care to CRS eligible children either at a CRS clinic or in the community. Five focus groups were held. Three focus groups were held in Phoenix and were attended primarily by those who provide services to children enrolled in the Phoenix CRS clinic; one of the three was specifically focused on the provision of behavioral health services. One focus group was held in Tucson and was attended primarily by those who provide services to children enrolled in the Tucson CRS clinic. A call-in focus group was set-up for Yuma area providers but there were none in attendance. A fifth focus group was held in Phoenix and was specifically focused on non-CRS primary care providers. Opportunity was provided for attendance via phone for the focus groups. Over 60 individuals participated in the focus groups, with at least six attending more than one (e.g., the general focus group and the behavioral health specific focus group). Three provided written comments and two requested and received interviews via phone. An offer of an interview was extended to two additional providers who had expressed interest, but no response has been received to-date. This section also includes comments from four individuals who responded to an on-line survey that was posted on the AHCCCS website; it is not known if they were family members, providers, or interested others.

A copy of the focus group questions is included in Attachment 1. The same questions were used for the interviews. Results are summarized below. Comments from those providers who primarily deliver

services to children in the CRS clinics are recorded separately from those who primarily deliver services in the community.

Overall Findings and Observations

There were some pervasive themes that threaded through the provider focus groups and interviews. These included the following:

- Coordination of primary care and specialty care is critical for children with special healthcare needs. Working as a team of providers is critical. Coordination of care can be aided by comprehensive, up-to-date, and accessible records.
- An integrated healthcare system for children with CRS eligible conditions should be as clear and simple as possible for families to navigate.
- The focus of the integrated healthcare system should be placed on what is best for children. This focus should be evident in all aspects and at all levels of the healthcare system.
- There should be options for families that take into consideration where they live, the availability of resources in their local community, child and family circumstances and preferences, and the child's condition.
- Providers should have the knowledge, skills, experience, and interest required to serve children with special healthcare needs and their families. Well-qualified primary care providers and specialists who are interested in serving children with special healthcare needs should have the opportunity to participate in the integrated healthcare system and not be excluded by having the health plan limit services to those provided by a single hospital or clinic setting.

Findings and Observations

Integrating Primary Care and CRS Specialty Services in the Same Health Plan

Providers were asked for comments about integrating primary care and CRS specialty services under one (or more) health plans. They were also asked about integrating other healthcare services for CRS eligible children, including Title XIX-funded behavioral health services, services provided under the Elderly and Disabled Program (EDP), developmental disabilities services, and services provided under Medicare.

CRS Providers:

Tucson

Those in the Tucson group agreed that having primary care and CRS specialty services covered by an integrated health plan makes sense. Benefits would include: easier access to a comprehensive medical record, better coordination of services (particularly pre-surgical), access to a broader array of resources, knowledge of the children and their families by all providers on the team, and perhaps reduced use of urgent care for primary care issues.

Phoenix

Most of those in the Phoenix groups agreed that an integrated health plan for children with CRS eligible conditions would be beneficial, especially for those children who require multi-specialty care. A major benefit would be that children would be seen by primary care providers who are familiar with their specialty care needs and who would, therefore, be able to take a more holistic approach. Furthermore, there would likely be increased communication, coordination, and consultation among providers. Other

benefits mentioned included facilitated pre-authorizations, reduced disputes related to payment responsibility, and possibly cost savings due to reduced duplication of services.

One provider brought up a concern that in an integrated health plan, the ability to leverage coverage might be lost, i.e., CRS pays for one service and the primary care plan pays for another related service that CRS cannot cover—unless, of course, all needed services were covered by the integrated health plan. Concern was also expressed about whether primary care providers would be willing to join an integrated health plan, if the payment rates are not higher and the risk is greater. Several providers expressed concern that well-qualified primary care physicians and specialists (those with the most expertise) might be excluded from participation in an integrated system, if the health plan had primarily an acute care focus and did not understand the complexity of serving children with special health care needs.

Some providers in the Phoenix groups commented that having services covered by a single health plan would not address all the current issues. Other issues that need to be addressed include: information flow, hours of clinic opening, access to medical records, after hours care, needed but uncovered services, and volume in the Phoenix CRS clinic.

It was noted that it would be good to provide families with a choice of whether to participate in an integrated health plan or to keep what they have.

Yuma

There was support for integration from one physician who sent in his comments.

Non-CRS Primary Care Providers:

Non-CRS primary care providers spoke about the importance of the medical home. Many of their offices currently serve as the medical home for children with special healthcare needs. They were concerned about what would happen if primary care and CRS specialty services were integrated in one health plan. Would all children have to be on the same health plan? Would all children have to go to the CRS clinic for primary healthcare? It was noted that they, as the primary care provider, take care of the child and the family in the context of the community. They are available to the families around the clock (and CRS is not). Families do not have to wait for long periods to be seen. The primary relationship should be with the medical home, not the health plan. Children should not be required to go to the CRS clinic to receive a service that can be appropriately provided in their community. Community pediatricians should not be locked out of this system.

It was noted that the Tucson CRS clinic has a model that is more functional. Primary care providers who come to the clinic see non-CRS children at CRS and can also see CRS children in their offices.

In an integrated health plan, it is possible that there would be more clarity about what services are covered and who can provide them. The concern was that a CRS denial not be required in order for a primary care physician to provide a needed service.

On-line Survey:

All were in favor of integrating primary care and CRS specialty services for children currently eligible for the CRS Program under one health plan.

Integrating Other Healthcare Services in the Same Health Plan

Tucson

The Tucson providers also saw benefit in integrating behavioral health services into the same health plan with primary care and CRS specialty services. They have a clinic support person who works with the Division of Developmental Disabilities (DDD); there are some administrative challenges and an integrated plan might help with those, but there was some concern about how this might work for non-medical home and community-based services. It would be useful to be able to order durable medical equipment directly for enrolled children. In general, the Tucson providers supported keeping medical services in one health plan and making the system as simple as possible for families.

Phoenix

With respect to integrating behavioral health services, it was noted that children with CRS eligible conditions have multiple and inter-related medical and behavioral health issues that are sometimes not well-understood by community behavioral health providers. Behavioral health conditions may be missed or misdiagnosed. Furthermore, there are limitations on covered services, which are currently inadequate to meet the needs of these children and their families. Finally, there is a lack of coordination between the physical health and behavioral health systems. It would promote quality coordinated care and be beneficial to families if behavioral health services were to be integrated into the same health plan as primary care and CRS specialty services. Some expressed a different point of view, noting that behavioral health services should be kept separate. One respondent commented that the expertise that does exist within the Regional Behavioral Health Authority (RBHA) might be lost if the systems were integrated and that more providers who are qualified to provide behavioral health services to children with special healthcare needs are needed in Arizona.

There was some confusion about the other healthcare programs/plans (e.g., DDD, Medicare). Those who were familiar with DDD expressed concern about integrating developmental disabilities services and most did not favor incorporating developmental disabilities into the integrated health plan at this time. However, it was noted that integrating developmental disabilities services with physical healthcare services might reduce some of the disputes about what is habilitation and what is rehabilitation. Some felt that integration with DDD would be too difficult to accomplish, that the philosophies of the programs were too different, and that important services might be lost in the transition. It was noted that DDD support coordinators can aid in coordination between the CRS and DDD systems.

Non-CRS Primary Care Providers:

Non-CRS primary care providers felt that it would be beneficial to have EDP and behavioral health services integrated with primary care and CRS specialty services, because so many children have multiple and interactive issues. The DDD system is very complex; there were differing views about integration of these services. The overarching concerns are meeting the needs of the child and quality of care.

An alternative view was expressed and that was that dollars should be tied to the child and should follow the child. The child would stay in the health plan of the family's choosing. There would be no CRS health plan and no behavioral health plan. Rather, each health plan would contract with providers

needed to deliver quality services to their members. A higher rate would be needed for children with special healthcare needs.

It was also noted that further conversations are needed with private insurers. Family-centered care with an appropriate rate, regardless of payor, is needed.

On-line Survey:

Responses were mixed in answer to the question of whether other healthcare programs should also be included in the integrated health plan and some expressed that they were unsure. One respondent commented: "There are way too many miscommunications due to various agencies picking up various costs." The respondent also expressed concern about the number of required meetings with the various agencies, which are duplicative and a burden on the family.

Behavioral Health Focus Group at Phoenix CRS Clinic:

The comments in this section relate to several of the focus group questions, but are included here because they focus on a specific population—children with CRS eligible conditions who need behavioral health services.

At the request of providers, a focus group was held for staff associated with the behavioral health program at the Phoenix CRS clinic. The consensus of participants was that behavioral health services should be integrated with CRS specialty services in the same health plan. The participants felt that this would be simpler for families who must deal with complex systems and who face multiple stressors. They felt that integration would also result in better care for children, many of whom need specialized behavioral health services and coordination of these services with their other healthcare. In their opinion, children with CRS eligible conditions need a true medical home.

There was an example given of a child with ADHD who required surgery. It was critical to manage the child's behavior, support the family, and work with the surgeon and pediatrician so that the surgery and follow-up resulted in a positive health outcome.

With respect to behavioral provider qualifications, participants commented that many children with CRS eligible conditions need to be treated by highly skilled professionals who understand the context in which their emotional and behavioral issues exist. A straightforward problem-focused, behavior management approach is often not sufficient to address the complexity of the issue. In an integrated system, the child and the family should have access to masters and doctoral level behavioral health professionals, as well as a psychiatrist, who have experience with this population. They should also have the benefit of team consultation between behavioral health professionals and the primary care and specialty physicians who are treating the child. A coordinated team approach would be particularly beneficial in medication management. One participant noted that having highly skilled behavioral health professionals working closely with primary care and specialty physicians can result in lower use of major tranquilizers and better clinical outcomes. With respect to qualifications of other medical providers, it was noted that they need an understanding of behavioral health and how behavioral health issues interact with other aspects of the child's medical care. Several participants spoke of the importance of interacting with the family in a holistic way for the good of the child with a CRS eligible condition.

It was also recommended that coverage be provided for more behavioral health services to CRS eligible children. As it is now, children sometimes go into the community behavioral health system, but end up coming back to CRS for behavioral healthcare that is coordinated with their CRS specialty services. This results in their service allocation being “used up” and the need still existing. Integration could be expected to make service utilization more efficient, but it was felt that more services were needed than are currently covered.

With respect to coordination of care for children with CRS eligible conditions who have behavioral health issues, it was recommended that there be a designated team coordinator who understands both the behavioral health and other medical aspects of care—perhaps a nurse coordinator. It was also noted that children with CRS eligible conditions who also have behavioral health issues can benefit greatly from services such as child life, social work, patient advocacy, and interpretation. They need a meaningful plan that includes services available through CRS and services and supports available in the community.

When asked about permitting young adults with CRS eligible conditions and behavioral health issues to remain in the CRS health plan, participants commented that there may be benefit to this in some situations and for some young adults. When discussing the issue of extension of CRS benefits past age 21, some participants brought up concerns about those age 18-21 who are still CRS eligible but must transition to the adult behavioral health system. It was noted that it is not uncommon for young adults to experience crisis at this vulnerable time in their lives.

Some of the key elements of effective healthcare for children with CRS eligible conditions who have behavioral health issues are good assessment, a comprehensive plan of care, competent providers, coordination among the various providers, availability of family supportive services, personal contact with the family, a shared organizational commitment to doing what is best for children and families, resources to do what each child needs (i.e., time and money), a long term health outcome focus, and communication among all involved.

Choice

Providers were asked if they favored having more than one integrated health plans so that families could choose.

CRS Providers:

Tucson

Those in the Tucson group agreed that having multiple integrated health plans would be redundant and result in higher costs.

Phoenix

This concept was challenging for providers in the Phoenix groups to understand. After clarification, there were mixed opinions about whether it would be desirable to offer families a choice of integrated health plans (that is, there would be more than one health plan offering integrated primary and specialty care). Most indicated that this would be very administratively complex for providers, but others expressed the opinion that competition would be beneficial to families (e.g., higher quality services, reduced costs, ability to switch if not pleased with one health plan). It was noted that many providers already contract with multiple health plans. If there were multiple integrated plans, the plans would each need to

contract with a lot of the same providers, especially specialists. Some thought that there would not be many health plans interested in bidding on an integrated healthcare plan. A concern was that having multiple plans would mean that there would not be a single “home” for the population of children with CRS eligible conditions and that competition might diminish accountability and commitment to achieving good outcomes for children. Furthermore, having multiple plans might result in different benefit packages and provider rates, thus making it confusing for both providers and families. If there were just one, then pediatricians from all over the state could join. It was noted that some areas have limited numbers of providers to recruit and there might not be a sufficient number of available providers.

Non-CRS Primary Care Providers:

The discussion began with a question—is there a need for more than one health plan?

If there were more than one, there might be increased competition and this might be beneficial to families (e.g., getting better services, more providers to choose from) and providers (e.g., faster payments).

It was noted that there are a finite number of pediatric subspecialists and they would need to contract with all the integrated health plans.

There was a question about whether one health plan could handle comprehensive services for all the CRS eligible children statewide.

After discussion, most agreed that it would be better if there were only one.

On-line Survey:

Three of the four respondents favored one plan and the fourth favored having a choice of integrated health plans.

Co-Location

Providers were asked if they supported the concept of co-located primary care and specialty services for CRS eligible children and which services were most important to co-locate.

CRS Providers:

Tucson

Tucson providers have had experience with co-located services, although the primary care services are covered by more than one health plan, while there is a single health plan for CRS eligible conditions. In the Tucson group, there was support for co-location. The CRS clinic in Tucson currently has co-located pediatricians. Participants stated that this model contributes to collaboration among providers and benefits the child and family. It is most important to co-locate diagnostic services and treatment, as needed.

Phoenix

In the Phoenix groups, it was noted that not all children and families have the same situation, needs, and preferences. Many commented that not all children need to be served in a multidisciplinary clinic setting; children with certain conditions are more likely than others to benefit from co-located services and a multidisciplinary team. Some wondered why some children had to go to a CRS clinic setting at all. Children whose needs are more complex and multi-faceted, as well as those who need social support and language interpretation, are likely to benefit the most from co-located services. However, some families live far from CRS clinics and would benefit from having their primary care provided close to home. In fact, having specialty services available close to home would also be beneficial especially for those children who only need to see one specialist. The providers agreed that there is not a single model that would work best for all children and all families. Family choice should be taken into consideration.

It was noted that it might be necessary to have multidisciplinary clinics that serve children with an array of special health care needs in order to maintain the financial viability of the clinic. It might be costly if only those with the most complex and multi-faceted needs were served in the clinic setting.

Co-location can be expected to support a multidisciplinary approach, but it is not sufficient to produce this. It was also noted that not all children have multiple appointments on the same day. One provider commented that he goes to the CRS clinic but is not there at the same time as others providing care to the same child; he said that there were no full team meetings. Regardless of where the services are located, having a shared medical record to which all providers contribute is essential for coordinated care.

Co-location can allow for the provision of a variety of supportive services, such as child life, interpretation, and social work. However, it was noted that these services can be and sometimes are provided in private offices as well.

Concern was expressed by one provider about bringing children who are sick into see their primary care physician when there are vulnerable children in the clinic waiting for their specialty services. From the provider's point of view, it was noted that some primary care providers might be reluctant to participate if they had to come to the CRS clinic site to provide services.

One option mentioned was having regionalized services, rather than having primary care co-located with specialty services.

It was noted that there are differences depending on the geographical area served. Some areas may be better served by having a centralized clinic, while others might be better served by dispersed services. It was noted that it is more challenging to provide centralized services in areas such as Phoenix, due to the size and spread of the urban area.

Yuma

A provider in the Yuma area commented that each child needs to have a medical home as close as possible to his/her home, but noted the value of having centrally located multidisciplinary clinics, especially for children with complex needs. These clinics should also be available to children with non-CRS conditions that require specialty care or surgeries.

Non-CRS Primary Care Providers:

Non-CRS primary care providers thought that the medical home should be the primary care physician's office. Specialty services could be delivered in specialty clinics, ideally geographically dispersed for the convenience of the families (e.g., hospital based). Families could choose which to attend. Most children see their primary care physician way more often than their specialists; they should not have to go to a central CRS clinic to do this. Concern was expressed that non-CRS primary care providers might be lost if all services were required to be co-located.

There may be some children who need to be seen at a CRS clinic, particularly children with multiple, complex, and long term conditions, e.g., spina bifida.

Electronic medical records that are shared among providers and telemedicine can be used to accomplish the same benefits as co-location. Family convenience should be foremost.

On-line Survey:

Three of the four respondents favored co-location and the fourth did not. One respondent commented that those who live more than a certain distance from the CRS clinic should have the option of receiving pediatric services closer to home; however, there should be coordination between CRS and the pediatrician's office and the pediatrician should have some specific services available, such as wheelchair access and availability of a interpreter.

Provider Qualifications

Providers were asked about provider qualifications in an integrated health plan.

CRS Providers:

Tucson

In the Tucson group, it was noted that the clinic has criteria for primary care providers. They must be experienced working with children with special healthcare needs. Working in the clinic setting gives them access to more resources. There is a comfort level among providers, staff, children, and families that has come from working together. Providers are willing and able to see children in their private offices in urgent situations.

Phoenix

There was no consensus on the issue of which credentials should be required or how credentialing should be done. In the Phoenix groups, there was a question about what sort of credentials might be required of primary care physicians who would be contracted to provide services to CRS eligible children. They would need to be capable and interested in working with this population; some noted that there is a need for more primary care physicians with skills and interest. If these providers were to receive a higher payment rate, care would need to be exercised to ensure the providers are truly qualified. Longer term, there is a need for creating an educational pipeline, e.g., a residency program for pediatricians interested in working with children with special healthcare needs. For specialists, provider qualifications should be as they are now. They have to be credentialed via a pediatric facility. There was discussion about not limiting this to physicians who are on staff at a pediatric facility. It was also noted that there is a need for more pediatric subspecialists.

Non-CRS Primary Care Providers:

There is a need for strengthening medical education in order to prepare a workforce with expertise in serving children with special healthcare needs. It was noted that Phoenix Children's Hospital has a large residency program.

Today, it is hard to define who is qualified, particularly on the primary care side. It is unrealistic to require additional training. Doing so would likely lead to the loss of competent, experienced providers. The focus needs to be on the whole child. The Academy of Pediatrics has a role in this.

Caution is needed if participation is incentivized so that inappropriate providers are not attracted to this work. Quality measures should be identified and applied, e.g., EPSDT rate, immunization rate.

CRS Programs

Providers were asked what aspects of the current CRS program should be preserved and what could be improved.

CRS Providers:

Tucson

Providers in the Tucson group highlighted the availability and quality of ancillary staff, such as child life specialists. These services enhance the medical services that are provided and are very helpful to both families and providers. They also value having lab, x-ray, and other such services available on-site. Collaboration among all those in the clinic reduces the need for the physician to do all the care coordination him/herself. Improvement could be made in the availability of transportation, meals for families, and time available to see each child.

Phoenix

Providers in the Phoenix groups noted as positives the ability to serve children with complicated needs, the ability to do a comprehensive screening and assessment, the multidisciplinary clinics, working in the same clinic structure, convenience, the therapists, good clinical protocols, availability of family support services (such as advocacy, child life, dietary, interpretation, psychology, and social work), follow-up on missed appointments, and nurses and nurse practitioners who know the child and family and follow them through the clinics.

Concern was expressed that if families had a choice of where to receive services, the benefits of the multidisciplinary team might be undermined.

Improvements needed include: timely appointments, more multidisciplinary clinics, a single in-charge person at the clinic, better quality control, and more staff (notably nurse coordinators and interpreters). It was suggested that Medical Assistants (MAs) be provided a higher pay rate if they speak Spanish, so they are able to help the interpreters. Several commented that the CRS staff is overworked and unable to do all that needs to be done.

A major concern voiced related to the information sharing and recordkeeping system. All providers need access to timely and comprehensive information via the CRS medical records. One provider commented

that he has his staff copy his records and takes them with him to the clinic because the records there are not up-to-date. It was noted that moving to an electronic medical record would not be a panacea, but would help. Another commented that he likes the paper record because you can see the child's whole history. One provider noted that promises about the development of a viable electronic recordkeeping system need to be kept.

One provider in particular who has worked with CRS for several years expressed serious concerns about his participation in CRS and the impact of current rules and processes on the quality of care he can provide. He commented that he is no longer authorized to see in his office children who are post-op and really need to be seen more often than they can get into the CRS clinic. He also expressed concern over denials of requests for various tests.

Several expressed concern about the profit motive in the system. Many noted that there were some evidence-based services that were not currently covered, e.g., genetic testing. They noted that genetic testing would improve the quality of care and possibly reduce costs. Physicians need to be involved in decision making and there needs to be transparency in explaining why services are denied.

Non-CRS Primary Care Providers:

There were varying levels of awareness among those in attendance about how the current CRS program works. Several noted that they sometimes refer children to CRS. It was noted that it is beneficial to have comprehensive evaluations for children with multiple and complex needs.

Concern was expressed about access to CRS records. One provider commented that the only way to know what is going on with a CRS patient is to ask the patient's family. This contributes to duplication of services and impedes coordinated care.

Concerns were raised about CRS specialty services provided to foster children covered by the Comprehensive Medical and Dental Program (CMDP). A participant commented that many foster parents are dissatisfied with elements of the CRS delivery system. One specific complaint related to wait times. The participant felt that it would be better if CMDP could contract separately for specialty services for its covered children, which might include contracting with a CRS clinic such as the one in Tucson.

On-line Survey:

Respondents commented favorably on the pediatric screening clinic, the multidisciplinary planning clinics for children with complex medical conditions, co-location of providers, a common medical record, care coordination, and access to case managers.

Concern was expressed about the need for ongoing authorization for services and rejections of authorizations, lack of specialized mental health care and limits on mental health care, and operation of the clinic by a for-profit organization.

Coordination

Providers were asked about care coordination—what is needed, for whom, when, and provided by whom.

CRS Providers:

Tucson

Tucson providers agreed that the social workers at the CRS clinic do a good job with care coordination and, therefore, they recommend continuing this approach. Care coordination services should be offered to all families. The care coordinator is a member of an integrated team that includes the nurses, physicians, therapists, social workers, and any others involved with the child. Membership in the team is fluid and may change as the child's situation changes. All have a role. The care coordinator does not function as gatekeeper, but rather is a facilitator of care.

Phoenix

In the Phoenix groups, there was agreement that providers need to function as a team and that there is a need for care coordination, especially for children with complex needs and prior to and after surgeries or other procedures. All families should be offered care coordination.

There were differences of opinion about who should serve as the care coordinator, but it was noted that it depends on what functions are being discussed. Some stated that the child's primary care physician should be responsible for care coordination; others questioned this. One commented that each specialty needs a care coordinator. Others felt that it should be a medical professional, such as a nurse. Others talked about the role as more of a facilitator, such as one sees at the Mayo Clinic. Regardless of who performs this function having an appropriate size caseload is critical.

It was noted that there needs to be a comprehensive written plan of care that is updated as needed. All those with a role in the plan would work with the care coordinator, who may or may not be the case manager.

There was agreement that coordination of primary care and medical specialty services should be coordinated, but there was not agreement about whether the care coordinator should assist the family with issues not related directly to the medical care of the child, e.g., housing. Some felt that it was important for care coordinators to address social determinants of health; other felt this role was too expansive for CRS. The providers in these groups were accustomed to having CRS staff provide coordination of non-medical services that impact the child's health and they saw the benefit of having this level of support for families.

There was agreement that the care coordinator should promote information sharing among team members. A point was made that the care coordinator should not be a gatekeeper, nor should they dictate what providers do or don't do.

Yuma

A physician from the Yuma area commented that there is a need for a care coordinator in the child's medical home and that the position should be filled by a nurse or social worker. There should be compensation for this function. If a practice is too small to support a full time care coordinator, it might

be feasible for there to be regionalized groups who provide this service.

Non-CRS Primary Care Providers:

Non-CRS primary care providers saw a critical need for care coordination and felt that it should be provided in the medical home, as it is under private insurance, but not necessarily by the primary care physician. Some noted that they provide care coordination in their practice but are not reimbursed for this. They provide this service because it benefits families whom they serve. Care coordination is best provided by a medical social worker, nurse, or nurse practitioner and there should be only one care coordinator for each child. Some non-CRS primary care providers saw the role of the care coordinator more broadly than the specialists did. Some commented that electronic medical records would help with care coordination, as this would provide immediate access to records. It was noted that using electronic records requires training in order to be effective.

One physician who submitted a written response commented: “The most important feedback that I can provide to you regarding the CRS system is the needs of families to have coordinated care. When a family receives some of their care at [a local hospital], dental care from a private provider, vision care from another private provider, and their primary care elsewhere, it is often overwhelming for the parent to coordinate all of this and keep accurate health records. Not only is it difficult to make all the appointments, but it is also difficult to keep all the recommendations straight.”

On-line Survey:

All of the respondents were of the opinion that care coordination was needed, but they were mixed in their opinions about whether it should be available to all or some and all of the time or only in certain circumstances.

Extension beyond Age 21

Providers were asked if they thought CRS eligibility should be expanded beyond age 21.

CRS Providers:

Tucson

Providers in the Tucson group spoke about the importance of timely and successful transition to the adult healthcare system for young adults with special healthcare needs, but noted that it would be beneficial to some young adults if they could stay in CRS. It was suggested that some family practice physicians be linked to the CRS clinic to help facilitate a smooth transition. It would be desirable if young adults who were still undergoing procedures could stay in CRS until the course of treatment was completed. It would also be beneficial for those whose lifespan was not expected to be long.

It was noted that making a transition to adulthood in general is very challenging for some children with special healthcare needs—there are emotional as well as medical issues. They need support in making this transition.

Sometimes the adult healthcare system does not have providers who are familiar with the CRS eligible conditions of young adults who are transitioning. If payment issues could be worked out, it would be

desirable to make extension of CRS available to those young adults who could benefit.

Phoenix

Providers in the Phoenix groups also stated that it would be beneficial for young adults to be able to stay in the CRS system, at least for some conditions (e.g., metabolic disorders, congenital heart defects, spina bifida) and in some situations. They commented that there is no good counterpart in the adult healthcare system for some CRS specialties and noted the need for the development of this expertise because those with special healthcare needs are living longer now than ever before. However, concern was raised about over-extending the CRS system and stretching resources too much if young adults were to be covered by CRS. Concern was also expressed about those with pediatric expertise treating adults.

Like their Tucson counterparts, the providers noted the importance of a successful transition to the adult healthcare system for most young adults and having an adult care system that has the competency to serve this population. There is also a need to examine covered services for young adults, regardless of which system they are in, e.g., therapeutic foods. It was suggested that perhaps some young adults could be extended in the CRS system but seen in physicians' offices rather than the CRS clinic.

Non-CRS Primary Care Providers:

Most non-CRS primary care providers agreed that some young adults should continue to be eligible, but an effective transition should occur for most. It was noted that transition for young adults with special healthcare needs is challenging, but there should be a seamless continuum of services, with care being provided by skilled physicians who are paid appropriately for services to this population. Currently there is no coordinated system of care for young adults with special healthcare needs who are transitioning to the adult healthcare system.

On-line Survey:

Responses were mixed, but three of the four respondents favored extension for some or all.

Inclusion of Other Family Members

Providers were asked for their opinion about including AHCCCS eligible family members in the same integrated health plan as the child with a CRS eligible condition.

CRS Providers:

Tucson

Providers in the Tucson group were supportive of including at least siblings. They already offer this option at the CRS clinic in Tucson. They recommended that parents be allowed to enroll in the same health plan but commented that the adults should be seen in the physicians' office rather than at the CRS clinic.

Phoenix

Providers in the Phoenix groups had mixed opinions about including other AHCCCS eligible family members in the same integrated health plan. Some thought it would be good to offer this as an option

for families and suggested that this might mitigate risk. Others expressed concern about the impact this might have on the availability of resources for children with CRS eligible conditions.

It was noted that if family members were to be included in the same health plan, they probably should be seen in locations other than the CRS clinic.

Non-CRS Primary Care Providers:

Non-CRS primary care providers are accustomed to serving multiple children in the same family and have seen the benefits of doing this. There were no comments about serving adult family members. However, it was noted that children with special healthcare needs should not be cut off from the rest of their family by a transition to an integrated healthcare model.

On-line Survey:

Responses were mixed.

Aids to Integration

Providers were asked what other than integration of primary and specialty services would promote service integration.

CRS Providers:

Tucson

In the Tucson group, the response was “accepting responsibility for caring for children with special healthcare needs.” They noted that children with special healthcare needs should have different prior authorization requirements than do children who do not have such complex healthcare needs.

Phoenix

In all the Phoenix groups, the most common response was improved information sharing, ideally via timely, comprehensive, functional, and accessible electronic medical records. The importance of follow through was also noted. The need for more primary care physicians who have experience working with children with special healthcare needs was mentioned.

Non-CRS Primary Care Providers:

Integration would be aided by family support services, such as those provided by Raising Special Kids and the Southwest Autism Research Center (SARC).

Other Comments

CRS Providers:

In the Tucson group, it was recommended that there be provision for a patient library, both print and on-line. In addition, they commented on the value that has emerged from Tucson Medical Center (TMC) and University Medical Center (UMC) working together to meet the needs of children with special healthcare needs and their families in Southern Arizona.

In the Phoenix groups, other comments included the following:

- Focus on the needs of children with special healthcare needs and their families; their needs and evidence-based medicine should dictate what is covered; ensure that needed services are available and provided.
- Address the issue of whether CRS is the medical home.
- Make it possible for experienced and interested providers to participate; do not allow CRS to become a “closed shop.”
- Build on the successes of the past and what has already been built.
- Improve integration between primary care and specialty services—whatever model is embraced.
- Improve relationships and the flow of information between CRS and various hospitals.
- Provide all services at pediatric facilities, not free-standing adult-focused facilities (e.g., MRIs).
- Keep it as simple and supportive as possible for families.
- Support collaboration among all those working on behalf of the child and family.
- There are children with non-CRS eligible conditions who could benefit from a CRS clinic model.

Non-CRS Primary Care Providers:

Non-CRS primary care providers added the following comments:

- There is a need for coordination of healthcare with school programs for children with special healthcare needs.
- There are urban/rural disparities which need to be taken into consideration in planning for integrated healthcare.
- The issue of disparities in payment rates between CRS specialty services and primary care services for children with special healthcare needs should be addressed.
- The lowest paid person often has key responsibilities; there should be appropriate compensation for care coordination and social work services.
- Having an identified medical home and care coordination are critical for children with special healthcare needs.

Several participants/respondents talked about the issue of private insurance coverage for children with CRS eligible conditions. This population needs to be considered in planning for an integrated healthcare system. One provider commented that private insurance companies get a break when families have both private insurance and CRS coverage. He is paid a lower rate for services provided via CRS than for similar services covered by private insurance. Others talked about the administrative complexities.

Many significant health conditions that can impact a child are not CRS eligible conditions; therefore, AHCCCS health plans will need to continue to have many pediatric subspecialists on the AHCCCS health plan networks to care for their member children with these special healthcare needs.

Healthcare provided to children in foster care (as defined in ARS 8-512) is the responsibility of CMDP. It was noted that, unless waived from the CRS carve-out, these children would be included in the integrated healthcare system. This would result in 10 to 20 percent of the children in CMDP being moved into another health plan for the primary care. Children with CRS eligible conditions are disproportionately represented in the CMDP population, both because children with special healthcare needs are at higher risk of abuse and because abuse has contributed to their medical condition.

Attention needs to be paid to the CMDP population in the consideration of an integrated healthcare system.

On-line Survey:

One respondent commented that “the power of CRS is in the ability to have high-level multidisciplinary care for the most vulnerable children in the state. These children are not only medically complex, but most are coping with poverty, social instability, and a host of psychosocial issues that have a significant impact on the family’s ability to follow through with complex treatment plans and cope with medical stresses. The CRS program should continue to be a multidisciplinary center-based medical program focused on improving long-term health outcomes while providing the highest level of care to these vulnerable patients. Incorporating primary care and expanding mental health services will have a significant impact on the long-term success of these patients.” The respondent also supported non-profit management of the program.

It was recommended that CRS include patients who have had a solid organ transplant because post-transplant care is very complex and multidisciplinary and requires long-term management for a successful outcome.

Attachment 1

Focus Group Questions

SLHI is working with AHCCCS to obtain family and provider input into the integration of CRS specialty services and primary care medical services for children currently eligible for the CRS Program. In collaboration with Raising Special Kids, we have conducted interviews with families of children receiving services from the CRS Clinics in Flagstaff, Phoenix, Tucson, and Yuma. We will add your input to the information we have obtained from them and share it with AHCCCS. There will also be an on-line survey posted to the AHCCCS website in the near future.

1. AHCCCS is considering integrating primary care and CRS specialty services for children currently eligible for the CRS Program under one health plan (not necessarily in one location and not necessarily only one health plan option – we'll talk about these issues later in the meeting). What questions does this raise for you? What do you see as the benefits of integration? What do you see as possible disadvantages or what concerns do you have?
2. In addition to primary care and CRS specialty services, some eligible children also receive Title XIX-funded behavioral health services, EDP services, and/or services related to developmental disabilities. Others receive Medicare services. Which of these should also be integrated into a single health plan? Which should not? Why?
3. At this time, only one AHCCCS health plan is contracted to provide CRS specialty services but families have a choice of AHCCCS health plans for their children's primary care services. If these services were integrated, do you think there should be more than one choice of integrated health plans? Why or why not?
4. Let's talk about the location of services. Do you think that primary care services should be co-located with CRS specialty services? Why or why not? At a minimum, which services should be located in the same place? Which are more appropriately provided in other locations, such as the physician's private office?
5. Thinking about provider qualifications, what are the implications for provider credentialing if primary care and CRS specialty services are integrated? Should there be changes to the current process? Are there services that primary healthcare providers in the integrated health plan should be able to provide to children enrolled in the CRS Program? If so, which types of services?
6. What is working well in the CRS Program that should be preserved? What would make the CRS Program better?
7. Families have been telling us that care coordination is important, particularly in some situations and at certain times, e.g., prior to a surgery. In an integrated health plan, what do you think care coordination should include? Who should be the care coordinator? What qualifications should they have? Should everyone receive care coordination? When/how long should it be provided? What are your concerns about care coordination?
8. Right now, CRS eligibility ends at age 21. Do you think it should be extended? For all, or only in certain circumstances? If extended, would this be at the CRS clinic or other locations within the

same health plan?

9. If primary care and CRS specialty services are included in the same health plan, do you think other children in the family and parents who are also on AHCCCS should be able to enroll in the same plan? Why or why not? Should they be seen in the CRS clinic or elsewhere?
10. In addition to integration of primary care and CRS specialty services within a single health plan, what would aid integration of these services?
11. Is there anything else that you would like to say to the team that will be working on plans related to an integrated healthcare delivery system for children who are eligible for the CRS Program?